

## 9: Justice and Care for the Noncompetent

### A. The Need for Legislation

In chapter four we considered the liberty of competent persons to consent or to refuse consent to medical treatment. To the extent that some such persons make decisions about their own future care which will be legally effective when they are noncompetent, the problem to be considered in the present chapter is mitigated. For here we consider the question: To what extent and by what means must the law, if it is to be just, require that medical care be supplied to persons who are not legally competent?

Among such persons, of course, there are many, such as infants and children below the age of consent (whatever the law determines this age to be), who never have been competent. Thus the issue to be considered here is unavoidable, no matter how many persons who are legally competent make effective decisions about their own later care. No system of "living wills" or designated agents solves the problem of what to do about the infant who never has been in a position to make a living will or appoint an agent.

Our primary concern in this chapter is how much care the law should require for noncompetent persons, particularly in cases in which care is necessary to save their lives. The reason for this emphasis is that the most serious injustice which can be done the noncompetent is to withhold care as a method of killing them.

There often will be levels of care above and beyond what the law can mandate which will be beneficial to persons and no imposition upon them. We must likewise be concerned to limit care so that noncompetent persons are not subjected to overtreatment, which also at times can be a serious injustice. Moreover, there are problems about the supply of care to noncompetent persons when it is needed for their health and well-being, even though not at all demanded to preserve life. The legal solution we shall propose toward the end of the present chapter will be of some help in dealing with all

such problems, although we will not focus upon them in the course of the discussion, since problems in which life is not at stake are only remotely connected with euthanasia, the focus of this book.

In chapter eight we argued against nonvoluntary euthanasia. If we are correct in holding that the law may never justly permit this practice, then neither can the law tolerate homicide upon noncompetent persons effected by the withholding from them of medical care. Homicide by omission is just as grave an injustice as is homicide by deadly deed, and the law forbids the former just as completely as it does the latter.<sup>1</sup>

However, it is much more difficult to recognize and to prove that a crime has been done by omission than that a crime has been done by commission. Not acting to save life is not always homicide, for it may not be possible to act; if it is possible, one in a position to act may not be aware of the need to do so. Even if one is aware that one could act to save a life and that this life will be lost if one does not act, there still will be no legally significant omission unless there is a legal duty to perform the act which one fails to perform.<sup>2</sup>

Generally speaking, parents are legally bound to care for their children, physicians for their patients, and so on. Such duties provide the foundation on which a prosecutor could argue that the withholding of care known to be possible and necessary to save life constitutes murder or another form of homicide by omission.<sup>3</sup>

However, there can be no duty to provide care—even care possible and necessary to preserve life—if that care would be such that no reasonable person would consider it appropriate and of real benefit to patients in their actual condition. On this basis there is no homicide in omitting to resuscitate a dying patient over and over again, for such efforts are not demanded by the ordinary standard of due care and probably violate this standard. In such cases physicians do not have a duty to do everything possible to keep patients alive, and so their nonaction is not an illegal omission, even though they could act and know that the patient surely will die if they do not.

It follows that the determination by law of what care will be required for noncompetent persons will be a determination of what neglect will be homicide. In times past, when hardly anyone was prepared to approve nonvoluntary euthanasia, special efforts to see to it that persons would not be homicidally neglected were unnecessary. Now, however, many favor active euthanasia, including nonvoluntary euthanasia, as we saw in chapter eight.

The law lacks adequate provisions and machinery to cope with the new situation, and so until now it has not defined very precisely the duty to provide care. Thus, persons are dying, as we shall show, by the unjust withholding of lifesaving medical care, but no prosecutions are taking place. The law must be concerned about such potential victims of homicide just as much as it is concerned about others who might be killed by deadly deeds. Other-

wise the requirement of equal protection is unfulfilled in respect to these persons. What is needed is a method of specifying before it is too late for the individual concerned what care cannot be withheld without homicidal neglect.

Children suffering from Down's syndrome sometimes are born with an intestinal blockage which will be fatal if not repaired by surgery, but which can be corrected by a fairly simple operation with a very high rate of success. In some cases in recent years surgery has been withheld from such children, although it is given routinely to babies needing it who are not unwanted by their parents. Legal and ethical commentators generally have regarded this withholding of care as unjustifiable discrimination against these infants.<sup>4</sup> Yet there is evidence that many physicians tend to ignore this consensus about what is due care for children afflicted with Down's syndrome; one survey indicated that half the pediatricians in Massachusetts would recommend non-treatment of the intestinal blockage when it is noted in such infants.<sup>5</sup>

Another fairly common kind of case which has been much discussed in the medical journals and elsewhere is that of the infant suffering from spina bifida. Spina bifida is a congenital defect resulting from the failure of the spinal column's two sides to unify perfectly, so that the child is born with a split in the column which may permit the spinal cord to protude, causing a hump on the back and preventing its normal closure. This defect results in damage to the nerves and lack of normal function in the part of the body below the site of the damage. Without treatment many such infants die from infection or from hydrocephalus, which is very often connected with the spinal defect.

In recent years it has become possible to close the opening in the back surgically and to treat the hydrocephalus. When full treatment is given, some of these children nevertheless die. However, many survive to grow up and are seldom severely retarded. Yet such persons suffer from many serious problems, usually including paralysis of the lower body, lack of bladder control, and other handicaps.<sup>6</sup>

Until the late 1950s not much could be done for children born with this defect, yet some survived. During the 1960s, as the new techniques became available, many centers having the facilities and expertise to use them vigorously treated almost all such children. They left untreated only those who were dying or whose condition posed technical obstacles to treatment. The percentage of survivors increased, but the burden of caring for children who survived and the handicaps under which they would still suffer became more apparent.<sup>7</sup>

Beginning around 1970, many physicians adopted policies of selective treatment, giving vigorous care only to infants whom they believed would survive and be able to enjoy a comparatively high quality of life. But there was no unanimity upon the standards for selection.<sup>8</sup> Moreover, at some centers in-

fants excluded by the selection procedures seemed to be dying more quickly than would have been the case before treatment was possible—although in those earlier days large numbers of such children were reported as stillborn who somehow probably would have been live births during the years when intensive treatment was the rule.<sup>9</sup>

Some advocate that nontreated infants should be given only normal nursing care and protected against suffering. Tube-feeding, oxygen, and antibiotics would be denied, but pain-killing drugs and normal feeding would be ordered. Treatment for hydrocephalus would be excluded absolutely, because “progressive hydrocephalus is an important cause of early death.”<sup>10</sup>

Others advocate periodic reevaluation of infants with spina bifida who survive early neglect, in order to prevent continuing survival of an infant in a condition growing constantly worse due to continued neglect.<sup>11</sup> Half-treatment can result in survival in much worse condition than would have been the case if treatment had altogether been excluded.<sup>12</sup> Consequently, some urge that active measures to bring about death be legalized as the only solution for infants excluded from vigorous treatment.<sup>13</sup>

Although some physicians put great stress on the distinction between killing and letting die, those who favor active euthanasia as a treatment of choice regard this distinction as a mere quibble.<sup>14</sup> From this point of view early death is sought as a management option, sometimes by the “active” withdrawal of treatment, a policy by which even fluids are withheld so that death will come quickly.<sup>15</sup> Others insist that nurses cannot be expected to lower their standards of basic care for a spina bifida infant, yet the nurse “has to be inspired to do the right thing” and not to save babies excluded from treatment by the selection process.<sup>16</sup>

Some physicians are beginning to express severe reservations about the whole effort to select infants for treatment and the consequences of this effort.<sup>17</sup> One thing is clear. The problem presented by infants suffering from spina bifida is not unique.<sup>18</sup> Similar problems arise with respect to patients of every age, when the prognosis with vigorous treatment is not for the attainment or restoration of healthy, normal functioning, and yet the prognosis without treatment includes the possibility of a prolonged and more severely damaged survival, which can be excluded with assurance only by withdrawing even normal feeding.<sup>19</sup>

It is often said that the problem of the extent to which the noncompetent ought to be given care has arisen because of the development of new medical techniques. These techniques make it possible to keep many persons alive today who only a few years ago would have died no matter what anyone tried to do for them. This explanation is partly correct, because every new power raises a new question concerning the conditions under which it is properly exercised and properly reserved.

But a far more important factor in the problem about care for the noncompetent—a factor which clearly would have given rise to this problem even had there been no progress in medical techniques during the last decade—is the shift from the older ethics based upon the sanctity of human life to the newer ethics based upon the quality of life.<sup>20</sup> Even some who accept legalized abortion regard as a legal fiction the denial of the personhood of the unborn by the United States Supreme Court. The transparency of this fiction leads directly from the legalization of abortion to the conclusion that infanticide also should be legalized, although a few strive to maintain a significant distinction between the killing of defective children before and after birth.<sup>21</sup> The view that unquestioning deference must be given to the parents' wishes with respect to the nontreatment of an already born child which is unwanted because of its defectiveness clearly is an extension of the view that a woman has a right to abort an unwanted pregnancy.

Examples such as that of the children suffering from spina bifida make clear that some sort of legal policy is needed to distinguish cases in which treatment ought to be required from cases in which it should be optional or even forbidden.

At present an infant or a person who has a legal guardian most often is treated in accord with the wishes of the parent or guardian, usually with these wishes shaped by physicians but ultimately respected by them. Some argue that this situation is quite satisfactory and that the law should remain aloof from it.<sup>22</sup>

The question of the noncompetent adult who has no guardian is less clear, for treatment now usually depends upon consensus between the attending physician and the patient's near relatives, but cases such as that of Miss Karen Quinlan reveal the limits of this arrangement. If the legislation we propose in chapter four were adopted, the physician clearly would have primary authority unless either a patient previously competent had established some control or a court overruled the physician's judgment or appointed and authorized a guardian to do so.

However, even if the locus of decision-making authority were clarified, there would still be a question whether the unchecked judgment of the parent or guardian and of the physician—even when the noncompetent patient's physician and family are in complete agreement—should determine the giving and the withholding of medical care. If in some of these cases—for example, that of the mongoloid child with intestinal blockage—there ought to be a legal duty to treat, then leaving matters as they are makes it almost impossible to prevent or punish this type of homicidal omission. By such an omission a person's life might be taken without due process, just as would be the case if active euthanasia were used as the method. Hence, the first problem is to determine what the law should be with respect to the substantive issue: To

whom is care due and under what conditions does it cease to be due? Only after this question is answered can one reasonably appraise various possible procedures for protecting the rights of everyone involved.

### B. Inadequate Solutions Criticized

Someone might argue that the proper course is to assume the consent of all noncompetent patients to treatment which would preserve or prolong their lives. However, this approach oversimplifies the problem by overlooking the fact that there is a duty to give care only when it is appropriate, and treatment is appropriate only when it is in the patient's interest.<sup>23</sup> In all the literature which we have seen concerning the case of Miss Quinlan there is a clear consensus—in comments both before the respirator was withdrawn, when it was generally expected she would die as a result, and afterwards—that such treatment was not appropriate. The New Jersey Supreme Court also reached this conclusion and thus gave a clearer legal status to the duty not to continue lifesaving medical treatment of noncompetent persons under certain circumstances.

While cases precisely like Miss Quinlan's are rare, the decision is being implemented in respect to a range of more or less similar cases.<sup>24</sup> Many patients on chronic hemodialysis find the treatment distressing both physically and psychologically.<sup>25</sup> Probably a person suffering from paranoia would find such treatment especially distressing. Would it be a duty to provide the treatment regardless of the distress? A recent Massachusetts Supreme Court decision, which we shall discuss in section I, upheld the refusal by the guardian of an adult with Down's syndrome to accept life-prolonging therapy for leukemia.<sup>26</sup> Some might criticize this decision, but hardly anyone will argue that an infant who is so badly deformed that death is inevitable regardless of treatment must be treated to prolong life as long as possible.<sup>27</sup>

Another proposed solution is based upon the use of the distinction between ordinary and extraordinary means of treatment.

In 1957 Pope Pius XII stated in an address to a group of medical specialists that while there is a moral obligation to use ordinary means to preserve life, there is no obligation to make use of extraordinary ones.<sup>28</sup> This distinction has been widely quoted in the literature concerning the limitation of treatment, and it played some part in the *Quinlan* decision. It also appears in the 1977 Arkansas statute which allows a member of the family or guardian to refuse the use of "extraordinary means" of medical care.<sup>29</sup>

However, as Paul Ramsey and Richard McCormick have pointed out, the distinction proposed by Pope Pius does not conform to the medical distinction between what is ordinary and what is not, and the force of the papal distinc-

tion is normative rather than descriptive.<sup>30</sup> Hence, to appeal to this distinction in the legal context is of little use, for this appeal merely raises once again the question what treatment is appropriate for a patient in a given condition, considering the patient's overall legitimate interests.

Moreover, the introduction of the ordinary-extraordinary distinction into law seems undesirable for another reason. Since the distinction comes from a religious context, it lacks a proper legal history. If it is to be used in law, then the body of traditional Catholic moral theology will have to become a source for legal judgments. This situation could be considered a violation of the First Amendment's prohibition of the establishment of religion.

Sometimes it has been suggested that the method of triage, which is used in military and disaster situations, should be applied for the selection of patients for medical care, with the implication that in this way defective and abnormal individuals might be justly excluded from treatment.<sup>31</sup>

In military medicine attention at times has been given to those sick and wounded soldiers who would be restored to active duty, while more seriously damaged soldiers were ignored. Clearly, this system treats individuals as means to the military objective rather than as patients who deserve equal respect for their personal needs. It is understandable enough in the situation in which persons are treated as expendable, but only a totalitarian society could make a general practice of such a method, and even then could do so only by clearly specifying the objectives for which persons were to be used.

In disaster situations a somewhat similar system has been used to select patients for care: Those are treated first for whom the physician can do a great deal of good with a minimum of effort. Those in very poor condition and who would require a large part of the available resources to survive are not cared for unless they survive until after those likely to benefit from fast treatment have been cared for. This method makes sense when there is an immediate shortage of facilities and personnel for care, since it distributes what is available in a manner most likely to save the largest number of lives.

However, the denial of care to noncompetent individuals is never argued for on such grounds; the justification is their prospective quality of life, or the impact of their care upon others or society at large. Clearly, disaster medicine is a special situation which would cut across the lines between competent and noncompetent, and require no special justification for ignoring anyone less likely to benefit significantly from quick treatment. When immediate pressures are not imposed by an unavoidable situation, the factors which require the special approach of disaster medicine are no longer present. The adoption of patient-selection methods suited to a disaster situation for the open world of normal society would be no more reasonable than the adoption of emergency-relief techniques as national economic policy.

Of course, many who advocate the selective nontreatment of defective

infants and other noncompetent patients urge that consideration ought to be given to the interests of the species, of society, and especially of the individual's family when a determination is to be made about treatment.<sup>32</sup> Those who advocate active euthanasia on the assumption that some human individuals fall short of criteria for personhood or on the assumption that the right to life of some persons can be extinguished by the conflicting interests of others obviously would support this line of argument.<sup>33</sup>

But if assumptions which would justify active euthanasia are excluded from consideration, then the impact of an individual's survival upon society or the extent to which an individual's family desire the individual to survive can hardly be accepted as just standards for limiting the duty to provide medical care.<sup>34</sup> If such standards were accepted, then the lives of some persons who happen to be noncompetent would be subordinated to less pressing interests of others. Such subordination would violate the due process and equal protection rights of noncompetent persons. These rights are recognized for the mentally ill and retarded no less than for other persons.<sup>35</sup>

Recent legislation in the United States requires that institutions and facilities receiving federal funding make the adjustments necessary to accommodate handicapped persons.<sup>36</sup> Also, there have been widespread efforts to make better provision for the education and training of exceptional children. In the face of these developments, it would be patently discriminatory to select any group of noncompetent patients for nontreatment in the interests of society or their families.<sup>37</sup>

The problems of families are touching and truly serious when they are faced with long-term responsibility for an infant or other family member who requires unusual care and who perhaps will never (or never again) be able to live a normal life. Yet families can obtain a good deal of public assistance and in other ways be helped to bear their burden.<sup>38</sup> Rather than legalize the exclusion of some noncompetent persons from treatment, additional assistance could be provided. In extreme cases parents can give up their parental rights and responsibilities.<sup>39</sup> In the past this process usually has led to institutionalization in a public facility. But in recent years much has been done in providing foster home care for individuals whose families could no longer care for them. Children with spina bifida have been accommodated in this way.<sup>40</sup>

In considering the unfairness of selection for nontreatment on the basis of the impact on society and the family if an individual survives with defects, it is instructive to review the experience of selection of patients for hemodialysis when such treatment was in very short supply. Some programs attempted to select by a committee decision based upon considerations of the social value of various candidates for treatment.<sup>41</sup>

It quickly became clear that committees tended to select according to their

own middle-class standards. The approach was strongly criticized and finally abandoned by at least one of the important facilities which had used it.<sup>42</sup> Random selection by taking patients on a first-come basis has been accepted as a fairer procedure.

Age also has been used and sometimes been imposed by law as a criterion for selection for hemodialysis. But this limit can be understood as an application of the disaster-situation method of triage if the specific modality of treatment is limited and life-expectancy from treatment is the decisive consideration.<sup>43</sup> In the absence of such medical indications and a real necessity to work within limits the use of age as a criterion seems to be an unusual case in which a group has been excluded from treatment on a discriminatory basis.

### C. Toward a Solution: The Demands of Justice

Generally, those who argue for the application of criteria based upon social and family interests to exclude some noncompetent persons from treatment also urge that the prospective quality of life of such individuals ought to be taken into account.<sup>44</sup> Moreover, some who do reject exclusion from treatment on the basis of the interests of others nevertheless urge that the potentiality of an individual for some level of human functioning must be present if the individual is to merit treatment necessary for survival.<sup>45</sup>

*Against this view the same arguments we proposed in chapter eight against nonvoluntary euthanasia tell.* We shall not repeat these arguments here. The crux of the matter is that different people have different quality-of-life standards. No one is able to judge fairly what a day of life is worth to some other person.<sup>46</sup> It would be arbitrary to accept quality-of-life standards as a basis for providing less protection for the lives of certain classes of individuals. Moreover, all of the injustices in the use of qualitative criteria uncovered in chapter eight, section E, will occur if these criteria are used in selecting persons for nonvoluntary euthanasia, whether the killing is accomplished by deed or by omission.

Sometimes it is argued that to refuse to select for nontreatment on the basis of prospective quality of life is to treat the disease in disregard of the well-being of the person afflicted with it.<sup>47</sup> However, as the literature on spina bifida makes clear, the adoption of such criteria amounts to a judgment that individuals with certain disabilities would be better off dead.<sup>48</sup> Once this principle is adopted, moreover, the distinction between nontreatment and active euthanasia can hardly be maintained, since efficiency in attaining the objective prescribed by the principle demands active euthanasia.<sup>49</sup>

It is worth noticing that if the infants being killed by neglect were slightly older when their prognosis became known, there would be much greater

hesitation about denying them treatment. It is easier for a family to reject a newborn whose prospective quality of life is as poor as that of the average child afflicted with Down's syndrome or spina bifida than it would be to refuse treatment for a four year old who was injured in an accident and had a similarly dim prognosis.<sup>50</sup> Many middle-aged competent persons are far from being perfect specimens; they do not refuse medical care for themselves on that basis.<sup>51</sup> In view of this fact it is hardly fair for them to refuse the treatment required by their newborn children.

It is often argued that toward life's end people become mere vegetables, who ought not to be kept alive. But it is prejudicial to classify some persons in this way. Moreover, there is a variety of types of persons who are considered to be in persistent vegetative condition.<sup>52</sup> Further, many of the elderly who are considered senile really are suffering from some condition which could be treated if sufficient attention were given to careful diagnosis.<sup>53</sup>

Richard A. McCormick argues that the alternative to appraising the value of care in terms of prospective quality of life is to treat all patients with every means available. He further suggests that the criterion of extraordinary means can be translated into considerations of quality of life.<sup>54</sup>

But this argument overlooks the fact that individuals who are competent can refuse treatment upon themselves without the intent to end their own lives, which would be the motive if they appraised their future prospects and decided they would be better off dead. Such refusal of treatment, including treatment without which life will be shortened, can be based upon objectionable features of the treatment itself, its side effects, and its negative consequences. An individual who has no desire to die can take such factors into account and decide that life without treatment, so long as life lasts, will be better than life with it. Such a decision is not a choice of death.

If justice is to be done to noncompetent individuals, an effort must be made to make such a decision on their behalf when they cannot make it for themselves. In this way the noncompetent will be protected from having treatment imposed upon them which they probably would reject if they were able to do so. Likewise, justice demands that no judgment be made on anyone's behalf that he or she would be better off dead. Not only would it never be possible to know with reasonable certitude that a noncompetent person would make such a suicidal choice, but the implementation by others of such a choice would violate the jurisprudential principles which argue against legalizing assisted suicide and voluntary euthanasia, discussed in chapters five and six.

The basic requirement of justice with respect to care for noncompetent persons is easy enough to state: The noncompetent person ought not to be denied that care which any reasonable person who was competent probably would desire in similar circumstances, and the noncompetent person ought

not to be given care which any reasonable person would refuse in a like case. The factor of noncompetence as such simply is irrelevant to one's need for care and the duty of others to provide it. If this factor is taken as an excuse to treat noncompetent persons otherwise than they would be treated if they were competent, an injustice is done.

The difficulty with this basic requirement is that clear as it is in theory, in practice its application is not at all clear.

The problems which arise with respect to treatment of noncompetent persons always or almost always are grounded in conditions causally related to, although distinct from, their very noncompetence—for example, in a condition of serious deformity, or of retardation, or of a poor medical prognosis, or of serious debility. Reasonable persons usually have not been in such conditions, although in some cases there is a class of individuals who have been and could express an opinion. For instance, many who suffer from spina bifida grow up and have normal or near normal intelligence. Also, while no one has been in Miss Quinlan's condition and is now able to express an opinion about what is appropriate treatment for one in such a condition, people can project a state of affairs in which they might be in such a condition.

Yet even when some individuals have been in one condition and many can imagine themselves in another condition, the requirements of justice cannot be settled by an opinion poll, although such polls might have some relevance. Competent persons can refuse not only inappropriate treatment but also appropriate treatment, and can refuse treatment without a good reason—for example, if they wish to commit suicide by omission.

Noncompetent persons cannot exercise their liberty; no one else can commit suicide for them. Therefore the wishes we can project for the noncompetent will only help determine what is just to the extent that these wishes conform to the public policy which does not favor suicide, but which only permits it out of respect for liberty. Thus what one would want if one were in the place of a noncompetent individual will point to what is just treatment of such an individual only if one's desires are not only intelligible but also compatible with a nonsuicidal intent. This distinction was unnecessary in chapter four but will be indispensable here.

Furthermore, even reasonable persons who reject both nonvoluntary euthanasia and suicide will not easily agree in all cases that medical care or other care either certainly must be supplied to or certainly must not be imposed upon a legally noncompetent patient. There will be many cases about which persons who are altogether reasonable and in no way willing to accept active euthanasia or suicide will disagree when it comes to setting the standard of care of noncompetents.

This is so because individuals who are not suicidal can quite reasonably disagree in very similar circumstances concerning the extent to which they

themselves wish to accept medical or other care. About all that one can be certain of is that anyone would wish palliative care—to kill pain and to minimize the discomfort of an unhealthy condition—as well as ordinary nursing care, and that anyone would refuse experimental treatments, those with a minimal chance of success, and those which would prolong the process of dying without giving at least some increased opportunity for action.

While these implications of the basic requirement of justice in respect to the noncompetent are very little, still they are enough to suggest that the withholding of all care—even including the comfort of fluids—to promote quick death must be regarded as *prima facie* unjust. At the same time the termination of active life-support systems maintaining the life of a dying and unconscious person must be regarded as *prima facie* just.

Although the Supreme Court of New Jersey invoked a supposed constitutional right to privacy in its resolution of *Quinlan*, it is important to notice that the court's decision in this case also rested upon the assumption that Miss Quinlan was dying.<sup>55</sup> Moreover, the court argued that most people would make a similar choice for themselves and for those closest to them.<sup>56</sup> No one, the court believed, would wish to endure the unendurable, to be held back from inevitable death for a few months, when there was no reasonable hope of being restored to consciousness and some degree of human activity.<sup>57</sup>

Every person receiving medical care is entitled to care in accord with the ordinary standard of medical practice—that is, the good care which a reasonably prudent physician of normal knowledge and skill would provide in similar circumstances. This standard of care has been given a certain precision through judgments in cases involving malpractice.<sup>58</sup> One might suppose that it would be helpful in defining the physician's duty toward noncompetent patients.

However, this standard is of little help. For, in the first place, the malpractice cases do not involve the withholding of care which causes the patient's death; they generally involve defects in what a physician does. Second, what constitutes due care is at least partly defined by that to which a patient consents or would consent, as we explicitly specified in chapter four, section I. Hence, the problem of determining what patients should be assumed to want cannot really be settled by the standard of due care except when this standard makes clear what anyone would want. Third, many cases of kinds with which we are primarily concerned in this chapter are too different from other cases to apply standards of due care, which depend upon analogies in which all the relevant circumstances are the same. Fourth, physicians would easily argue that the practice of withholding care *precisely in order that* patients will die is becoming accepted as standard medical practice.<sup>59</sup>

Perhaps cases in which children afflicted with Down's syndrome have been permitted to die would be judged to be instances of malpractice; surely they

would if the parents desired good care for the child and the physicians failed to perform the necessary surgery. However, as things stand, the physicians rely upon the refusal of the parents to consent, and the possibility of malpractice toward the infant patient, whose rights can hardly be reduced to the rights and interests of the parents, remains unexplored because no one with standing to sue for the wrongful death of the infant comes forward to do so.

#### **D. Inevitable Economic Limits and Justice**

In some discussions of the extent to which there is a duty to provide medical care it is pointed out that care can be very costly.<sup>60</sup> Can at least some classes of noncompetent individuals—for example, children who are born afflicted with severe defects due to spina bifida—be denied care on the ground that care for them simply would be too expensive? To answer this question it is necessary to consider the prior question as to what is each individual's fair share of medical care. For this we must consider what medical care is.

Ordinary nursing care and medical care must be distinguished from each other. Ordinary nursing care includes those things patients would do for themselves if the strength and will to act were not absent; in the case of infants it includes those things which a mother would do for her child. Thus nurses see to it that their patients are fed, kept clean, kept warm, changed in position from time to time, and so on. A professional nurse provides in addition to ordinary nursing care medical care under a physician's direction and in this capacity functions as an assistant physician.<sup>61</sup>

Medical care is the application of means of preserving life, promoting health, and easing the pain and discomfort of disease and injury when the means applied require the special training, knowledge, and skill of a person whose profession it is to engage in such work. The province of medical care is to examine with trained skill, to diagnose on the basis of expert knowledge and professional experience, to plan and prescribe treatment in accord with the state of the art, to perform tests and treatments using equipment and instruments which might endanger patients if they were used without special skill and care, and so on. What is medical care in a proper sense should be defined in terms of the concept of health, and health itself must be limited to the well-functioning of a person—in the present context, to organic well-functioning.<sup>62</sup>

Because of the distinction between ordinary nursing care and medical care it would be unfair to argue that noncompetent persons must be denied whatever is their fair share of medical care on the ground that the total cost of their care, including nursing care or maintenance in a public institution, will

greatly exceed the average amount which can be spent for each member of society for medical care. If anyone wishes to argue that society cannot afford to feed nonproductive consumers, that argument should be proposed in a straightforward way, without confusing the cost of other necessities of life with the cost of medical care. Exceptionally bright and able children also are expensive to bring up, and exceptionally well-to-do persons also consume a great deal more than the average share of the gross national product.

In the allocation of resources America has large and unsolved problems concerning the priority which ought to be given to medical care in general and to various modes of medical care. At the level of delivery of care there sometimes are problems as to the allocation of limited facilities—for example, kidney dialysis machines or transplant operations.

In general, we are not concerned here with such problems, for they affect the competent as well as the noncompetent and are only remotely related to euthanasia. However, we shall briefly discuss the need to limit medical care at some level and the manner in which this might be done without unfairness to noncompetent persons or to others who happen not to be in a strong position to obtain care which would be of benefit to them.

Many criticisms have been made of the existing health-care system as a whole. Some doubt that health-care ought to be treated as a commodity; it is argued that physicians have achieved a monopoly such that they exploit patients by charging for their need. Others urge that the allocation of medical resources is faulty—for example, in putting so little stress upon preventive medicine.<sup>63</sup> We are not concerned here to argue these issues. Whatever the injustices in the present system, they affect the competent as well as the noncompetent. Our concern here is with the special issue of justice which is involved if noncompetent persons are taken advantage of so that treatment due them is withheld or treatment a competent person would reasonably and legitimately refuse is imposed upon them.

It is clear that society has some common commitment to the provision of medical care. Public funding is devoted to health in many ways, and society recognizes, licenses, and supports the medical profession—and does the latter at a very high level. Still, there are many other purposes, such as national defense and education, to which the society also must direct its scarce resources. It will never be possible to do everything possible in any one field. As medical technology develops and evermore expensive forms of treatment are devised, the inevitability of an absolute limit on expenditures, even when life is at stake, will become even clearer.<sup>64</sup>

There already has been some experience of this situation with the introduction of kidney dialysis, which is too expensive for most people to afford. Not all who could benefit were treated; various methods of selection were developed. In some cases ability to pay was a disqualification for admission to a

program. United States government funding of dialysis was widely criticized on the ground that other, similarly expensive treatments would not be able to be made available with public funds to all who might benefit from them.<sup>65</sup>

Given the system of health-care delivery which actually exists, a fair share of health care available to individuals seems to be based upon need—which seems to be a very reasonable principle—limited by ability to pay.<sup>66</sup> All physicians can refuse to accept any noncompetent patient for care if they are unwilling to provide service without payment and if there is no source from which payment might be expected. Anyone having care of a noncompetent person in need of medical treatment is innocent of neglect if every effort is made to obtain treatment, but none is available because there simply is no way to obtain it. But this situation obviously does not justify what we are mainly concerned with in this chapter: the purposeful withholding of medical care from noncompetent patients who are *already* patients of some physician.

It is worth noticing that cases discussed in the literature in which care has been withheld so that individuals would die do not seem to have hinged upon immediate financial problems. One reason for this might be that when care is not obtained because of financial difficulties, this situation does not appear to anyone to involve an ethical problem which requires an argument in its defense. Another might be that although the medical costs involved in caring for defective infants and other noncompetent individuals often are substantial, much of this cost can be reimbursed from public funds and from insurance.<sup>67</sup>

At the public level there are limits on what can be allocated for medical care. Yet up to the present there never has been a policy by which a particular group has been defined and systematically denied a share in available medical resources.<sup>68</sup> If, as some fear, advancing medical technology threatens to absorb an ever-increasing share of scarce resources, limits can be established without selecting particular groups for discriminatory treatment.

There would be many ways to accomplish this purpose. One would be to set dollar limits to the total amount of public funds which could be paid to or on behalf of any single individual to reimburse medical and hospital costs during a year and/or during a whole lifetime. These same limits could be applied by statute to the total which could be received or paid on one's behalf from ordinary health and major medical insurance, including all group insurance. If individuals wished to spend more, either on an item by item basis or by buying special individual insurance to supplement the limited policies generally available, they could of course do so. However, no one would be considered to have a legal duty to pay for anyone's care beyond the established limits.

Arrangements such as these would prevent the situation which is often projected as a specter: a cure for cancer which costs millions of dollars for each patient or a means of keeping people alive for hundreds of years.

### E. Nonsuicidal Reasons for Refusing Treatment

Both nondying and dying persons might have reasons for considering the refusal of treatment without which life cannot be saved or prolonged. However, such considerations are far more likely to appeal to a person who is dying. Hence, any legal policy with respect to the refusal of treatment on behalf of noncompetent persons must be based upon a clear concept of the condition of dying or the process of terminal illness. How can this concept be defined?

Sometimes it is suggested that everyone is dying from the very beginning of life.<sup>69</sup> But while it may be true that the decline of vitality is a lifelong process, to identify this process with the condition of dying is to defy common sense and the ordinary use of language, which notes an important distinction between aging and dying. Again, it is urged that to determine whether an individual is dying one must know that individual's previous history.<sup>70</sup> A patient's history may be helpful in diagnosing an existing condition, but extreme ill health and debility compared with a prior condition of well-being and vigor is not by itself enough to determine that one's condition is terminal.

Again, dying is sometimes confused with the condition of incurable illness.<sup>71</sup> But many conditions such as diabetes are incurable, and yet not every diabetic is dying. Nor will it do to say that dying is a condition intermediate between full life and full death.<sup>72</sup> Many who are declining and debilitated might be said to lack full life, but such persons are not dying; in another sense, as long as one is alive, one has full life, since being alive is not a matter of more and less.

If we consider the conditions under which we say that someone is dying, we find that generally this is not said unless one knows some cause which is already at work in the individual and is expected to be fatal. For example, a friend may seem very ill and rapidly declining, but is not said to be dying until the cause is diagnosed as a condition which cannot be reversed—for example, an invasive and inoperable carcinoma of a vital organ. At the same time, if such a cause is known to be engaged in its inexorable operation, a person who seems quite vigorous can be called "dying," although not perhaps "terminally ill." The cause which is identified must be one which cannot be removed or counteracted by any treatment available under the actual conditions.

A process which is potentially fatal and irreversible will not lead to the judgment that the individual is dying if there is still any significant possibility that the individual will die by the unexpected intervention of another cause such as an accident or another disease. In effect, to say that someone is dying is to make a prediction with considerable assurance that a condition already known to exist will be fatal—will be listed as at least the underlying cause of death on that person's death certificate.

On this conception not everyone who has an incurable condition which normally is eventually fatal should be said to be dying. In many cases there is a prospect of prolonged life with good treatment, so that there is a significant probability that an unrelated factor will cause death. Thus, someone afflicted with a form of cancer which can be held at bay for several years would not be considered dying even if the condition will kill if something else does not do so first, because such an individual can also die of a heart attack, an automobile accident, or some other cause. Moreover, decline and debility, particularly if it is appropriate to an individual's age and life history, would not be considered a process of dying; "old age" is no longer an adequate explanation of anyone's death.

Nevertheless, there are times when one can be certain a person is dying without being able to specify a precise cause of death. These are cases in which an individual's condition is so extremely debilitated and so rapidly worsening that an observer can be certain that *some* fatal cause is at work. For legal purposes cases of this sort will not be very important, since usually physicians can diagnose the condition of which anyone is dying; if the condition cannot be diagnosed, they will assume a patient is dying only at a point at which the withholding of treatment which would prolong life could not be considered unlawful, and the imposition of such treatment could hardly be considered due medical care.

The concept of dying has an inherent vagueness, and the criteria for recognizing a person as dying are not always easily applied. The vagueness of the concept arises because it depends upon the probability that some existing condition will be the cause of death, and this probability is not precisely specified. The criteria for recognition can be difficult to apply because misdiagnosis is not uncommon; treatments considered ineffective sometimes succeed. Dying patients sometimes recover and live for years.<sup>73</sup>

From the point of view of the problem we are concerned with in this chapter the distinction between persons who are dying and those who are not is important for two reasons. First, as noted above, considerations on the basis of which a person might choose to refuse medical treatment which is available are far more likely to appeal to a dying person than they are to one who is not dying. Thus law must take into account the fact that an individual is or is not dying if appropriate refusal of treatment or consent to treatment is to be constructed on his or her behalf.

Second, although someone who could provide care and who has duty to do so will be negligent if such care is not provided, such negligence could hardly be held to be homicidal unless it could be shown that a reasonable person could predict and the negligent person did foresee that death would result—that is, that the negligence would *cause* death.<sup>74</sup> Depending upon the conceptions of causality which are adopted, a court would find it more or less

difficult, or even impossible, to find that negligent care of an already dying person caused death or even certainly hastened it.

Even a dying person might desire medical treatment of various sorts. One surely would desire palliative care to limit suffering and discomfort, to remove annoying symptoms. One might also desire more active treatment if it held out the promise of a remission of the process of dying sufficient to allow one to do or to experience something one wished to do or to experience.

Ordinary nursing care also would be desired, both because lack of it would increase suffering and because the personal aspects of such care generally are a comfort to one who is dying. Even here, of course, there would be limits. If being fed caused a dying person considerable discomfort and no apparent satisfaction, and if the pains of hunger could be allayed without these untoward consequences, then it would not be unreasonable to assume that such a person would prefer not to be fed.

But while a dying person might desire various forms of care, such a person also might well choose to refuse therapy of a more active sort, even if aggressive treatment could prolong life considerably. Several considerations might be regarded as adequate grounds to refuse treatment.

First, sometimes treatment is experimental or otherwise risky. A person who is dying, just as one who is not, might prefer to avoid treatment which carries with it some danger of bringing about an unexpected result, such as immediate death, increased discomfort, or an alteration of one's disposition.

Second, some treatment is itself painful or brings about other experienced conditions which are undesirable. One who is dying might well choose not to undergo pain, to prefer a somewhat shorter but more pleasant life.

Third, in many cases the requirements for the application of medical care would interfere with the activities and experiences which one desires during the time remaining. For example, one might well refuse care which would take one away from one's family or one's work. One might prefer to spend one's last days in a pleasant retreat rather than to spend one's last months in an intensive care unit.

Fourth, many people object to certain forms of care on the basis of some principle. A Jehovah's Witness might refuse life-prolonging or even lifesaving blood transfusions. Anyone might refuse a heart transplant if the heart had to be taken from another not already dead.

Fifth, there are a variety of reasons why persons find medical care psychologically repugnant. Those who are not dying generally overcome this repugnance; those who are dying might well consider such feelings adequate ground for refusing life-prolonging treatment. Among the factors which make medical treatment repugnant are shame or embarrassment at being seen and touched by others, humiliation at being dependent upon other people and even on machinery to carry on one's vital functions, impatience with treat-

ment which does not yield felt benefits, resentment against physicians and other persons administering care who seem too detached and insensitive or too professionally cheerful and optimistic, and irritation at being aroused, fussed over, and disturbed. Such psychological repugnance to treatment provides much of the content of the concept of indignity which lends plausibility to the slogan "death with dignity."

Sixth, in many cases medical care for one individual makes very severe demands upon others—for example, the depletion of a family's financial resources or the tying up of medical facilities which could actually be put to use for the benefit of others. Persons who are dying might well prefer not to impose such burdens on others. Here we are considering, not costs and resource allocation as an excuse for neglecting the care of individuals, but the probable legitimate desires of the individuals themselves which only indirectly reflect these factors.

#### **F. Reasonable Presumptions for the Noncompetent**

Although in general persons who are legally noncompetent can be presumed to consent to care in accord with the ordinary standard of medical practice to the extent that such care will preserve or prolong life, this presumption admits of exceptions. While the preceding argument shows that considerations based upon an individual's prospective quality of life if he or she survives ought not to be allowed to weigh against providing care—since this would amount to the judgment that the person would be better off dead—considerations on the basis of which the person would themselves probably prefer that treatment not be administered cannot be ignored without unjustly imposing upon the noncompetent person.

It might be urged that the limitation of care where appropriate will be assured if the ordinary standard of medical practice is properly understood and followed. But except to the extent that this standard itself takes into account the circumstance of the patient's personal consent to or refusal of treatment—the very circumstance here under consideration—the ordinary standard of medical practice often will indicate that treatment be continued in cases in which from the patient's viewpoint limitation would be appropriate. This discrepancy might arise because the present standard of medical practice in respect to certain forms of treatment is to continue applying them as long as there is any possibility that they will prolong life. It might also arise because the reasons why a patient would prefer not to have certain kinds of treatment continued are personal ones which lie beyond the physician's normal perspective and competence to evaluate.

If a noncompetent person is dying and permanently unconscious, then the

reasonable presumption is that medical care to prolong life is inappropriate, since most people would find care under such conditions psychologically repugnant and inconsiderate of others. Still, most people would wish to be treated as living persons until they actually die—and to have their bodies treated with decent respect afterwards. The provision of ordinary nursing care, to the very limited extent to which it can be given without medical expertise to use special equipment and techniques, seems to be required for due respect to even permanently unconscious dying persons, considered as living persons until they die.

If a noncompetent person is dying but is not always unconscious, then in addition to ordinary nursing care there is a reasonable presumption that palliative medical care is appropriate. Whether life-prolonging treatment is appropriate is a matter of judgment. On the one hand, the fact that an individual is dying may be enough to indicate that care would be refused for one or more of the reasons stated above. On the other hand, if an individual is able to engage in any activities or to have any experiences which he or she might wish to continue, and if none of the considerations on which a refusal of treatment would be based seems to apply in the particular case, then consent to treatment ought to be presumed, even though there is no likelihood of recovery to a point at which competency would be regained and even though many people would regard the quality of life of such an individual to be negative.

If there is a probability that patients will recover sufficiently to do things or to experience things which they might value, and especially if there is a significant possibility that patients will recover enough to become competent to make their own decisions about care, then the desirability of treatment increases. However, the considerations on which treatment might be refused also must be weighed, and the probable choice of the patient projected from the evidence available.

In most cases any permanently unconscious patient can be presumed to be dying. Generally the underlying cause of unconsciousness probably will eventually cause death either directly or by complications resulting from the continuing state of unconsciousness itself. However, inasmuch as a person is not dying if lifesaving treatment can reverse the probability of death from an existing condition, a permanently unconscious person is not necessarily dying.

Even in such a case it seems to us reasonable to assume that such a person would refuse medical treatment. Some considerations which weigh against treatment would appeal to most people. This appeal need not be dismissed as prejudiced because everyone could at some time find themselves in the condition described. Moreover, in a permanently comatose condition there is no opportunity for doing and experiencing, which most people would value, to offset the appeal of reasons for rejecting medical treatment.

It might be objected that the last point depends upon an evaluation of the quality of life of a permanently unconscious person. But this is not so. No judgment is made that the person would be better off dead than living in the given condition. However, the given condition of the patient must be taken into account to notice whether there are any positive aspects of the patient's life which a reasonable person would regard as outweighing those considerations other than suicidal ones on the basis of which a person might refuse treatment.

The process of weighing the alternatives against one another, moreover, is not an attempt to calculate the net value of each alternative; rather, it is an attempt to conjecture what choice people themselves would make. Here what choice most people who considered the matter would make with respect to themselves if they were ever in the condition described is relevant evidence upon which to ground the conjecture, especially if the common opinion is shared by persons who do not consider suicide and euthanasia legitimate.

If a permanently noncompetent person is neither dying nor permanently unconscious, the general presumption in favor of consent to lifesaving treatment according to the standard of good medical practice will usually stand as correct. Most competent persons who are not dying accept lifesaving medical treatment regardless of the aspects of the treatment and its effects which might make it repugnant, and there is no reason to presume that noncompetent persons would take a different view of the matter.

If a person is only temporarily noncompetent and is neither dying nor permanently unconscious, then the presumption in favor of consent to lifesaving treatment is even stronger, since the condition in which one would be able to make choices for oneself is likely to be valued both for the use of liberty itself and for other activities and experiences which one might enjoy.

Even in a case of this sort, however, considerations on the basis of which a person might choose to refuse lifesaving medical treatment cannot be wholly excluded. The prospective quality of life subject to limitations and handicaps is not a factor which should be taken directly into account. Any judgment that a person would be better off dead than surviving with limitations and handicaps is illegitimate, for refusal of lifesaving treatment projected on this basis amounts to suicide. The law can hardly accept the conjecture that anyone would commit suicide without accepting the practice as legitimate, not merely as something to be tolerated out of respect for liberty.

Although a prognosis of a life which would be considered by some to be of poor quality cannot be taken into account, yet the actual condition of a person must be considered in weighing the significance he or she probably would attach to various factors which might make the treatment itself seem repugnant.

Moreover, in many instances lifesaving treatment is only more or less

probably going to succeed. In other words, in many cases a person who is not dying inasmuch as possible treatment could reverse the probability of death from a given cause nevertheless probably will die due to that cause. For example, a patient who has a condition which might be remedied with surgery which has a high mortality probability is not dying inasmuch as the surgery *could* succeed but will probably die due to the condition since the surgery *probably will not* succeed. When the likelihood that a possible treatment will succeed in saving life is low, a patient who would be considered dying except for the possible success of the treatment can reasonably be considered to weigh more heavily factors which would make the treatment repugnant than if the probable success of the treatment were high.

### G. Application to Cases of Defective Infants

In terms of the preceding principles one can consider the judgments which ought to be respected with regard to some of the kinds of cases discussed in section A.

An infant suffering from Down's syndrome who needs a fairly simple operation to remove an intestinal blockage and who is otherwise in good condition certainly ought to have the operation. No one who was competent would refuse such a simple operation for themselves, and no normal child would be denied it. The undesirable aspects of the surgery itself and its consequences are slight and the prospect of success with the operation good, while death is inevitable if the surgery is not done. The only reason for denying the infant the treatment is the impermissible one of its antecedent congenital condition. The treatment is withheld only for fear that it will succeed, when it is assumed that the patient's life ought to be terminated either for the benefit of others or because it is considered better off dead.

Infants born with spina bifida present a more complex problem. Some are dying. For them the withholding of surgery and other medical treatment, except palliative and ordinary nursing care, would be acceptable. Others are not dying, for there is a probability that good care will be lifesaving. The presumption in such cases must be in favor of treatment. However, in cases in which an infant is in very bad condition so that the probability of survival although real is comparatively low and the expected course of treatment is unusually long and difficult, one might conceivably conjecture that a person in this condition would refuse treatment to avoid the pain, the interference with life, the disturbance, and the inconvenience to others which the treatment would impose.

The advice of individuals who have survived such treatment and who do not approve suicide and euthanasia would be of great value in making a

reasonable conjecture in a case of this sort. If such persons considered the treatment, when its probability of success was not good, of sufficient worth to justify the adverse aspects of the treatment itself and its consequences, then one could say with confidence that a person in such a condition probably would prefer to be treated. This conclusion is especially compelling when one considers that failure to treat someone who is not then killed by withdrawal of ordinary nursing care is likely to lead to survival of the individual in a far worse condition than would have obtained if vigorous treatment had been undertaken at an early stage.

The literature which we reviewed on the problem of selection of children for medical treatment from among those afflicted with spina bifida makes clear that most—if not all—who advocate selection argue on the basis of social interests, family interests, and the prospective quality of life of the child who survives. Little weight in their argument is placed upon the considerations which might render the treatment repugnant to the afflicted individual. The fact that physicians do treat infants with spina bifida, no matter how poor their prognosis, if parents demand treatment also suggests that there is no strictly medical justification for withholding treatment.

The fact that most people who are competent would desire treatment for themselves or their already accepted children if an accident created a situation analogous to that in which the spina bifida is born confirms the conjecture that such an infant would consent to treatment. The analogous situation we are imagining would be one in which an accident put an individual's life in peril, but there remained a substantial chance of saving it by a rather long and difficult course of treatment, with a prospect of imperfect recovery to a life subject to many limitations and disabilities, sometimes even with reduced intellectual powers.

This is the kind of situation in which individuals every day urge physicians to do everything possible to save life, on the assumption that where there is life there is hope. No one gives up as easily upon his or her own life or upon the life of a wanted child as do the physicians who exclude spina bifida infants from care. It is clear that exclusion in most cases—except those in which the infant is dying—is based upon a judgment that the prospective life is not worth preserving.

#### **H. The Case of Miss Karen Quinlan**

As we noted previously, when the *Matter of Karen Quinlan* was heard by the New Jersey courts, the general assumption was both that she was permanently unconscious and that she was dying. On these assumptions it was not unreasonable to conjecture that in her condition she would refuse at least the

intensive care she was receiving and to which her family objected. Psychological repugnance and consideration for others who might make use of the resources and facilities might have been sufficient considerations to warrant a reasonable choice against treatment in the intensive care unit. Also, although it was not established that Miss Quinlan held any principle which would have required her to refuse intensive care, it was plausibly argued that she accepted a position according to which the refusal of such care was a morally acceptable option.

Even if it had been believed that Miss Quinlan was not dying, a very plausible argument can be made that the considerations weighing against care would have prevailed in a reasonable judgment by her. An individual who stands to gain only the preservation of life from intensive care, with no prospect of recovery of abilities to act and to experience, might well prefer that others have the advantage of the resources and facilities used in this way, and might well consider intensive care so repugnant as to be unendurable. It also is worth noticing that many people would consider refusal of care in such a case morally obligatory on the ground that consent to it would express an attitude of clinging greedily to life, an attitude hardly compatible with a decent respect for the interests of other people.

Nevertheless, the Supreme Court of New Jersey can be faulted for not pursuing more carefully the question of whether Miss Quinlan was dying or not. It could be argued that the damage she has already suffered will very probably be the underlying cause of her eventual death. If so, then she is dying, and we doubt that the law ought to require that she be given any medical care at all. The use of antibiotics to fight infection and the feeding of a special formula by tube surely are forms of medical care. Ordinary nursing care probably would not keep Miss Quinlan alive for long, for even if she is able to swallow, the effects of malnutrition and infection probably would end her life in a short time.

But if the law cannot require that a person in Miss Quinlan's condition be given medical care if she is dying, it cannot forbid all such care and especially cannot forbid less aggressive forms of care if a person is not dying—that is, if the care really maintains life. Life is a good to which most people cling, and the less aggressive forms of care are neither so repugnant nor so incompatible with the interests of others in alternative uses of resources and facilities that one need assume that a person in Miss Quinlan's situation would refuse the medical treatment she now receives.

In other words, we think that Mr. and Mrs. Quinlan have made a judgment on their daughter's behalf which is well within the bounds of reasonable conjecture, although it is not the only reasonable conjecture which they might have made. It would also be reasonable to suppose that a person in Miss Quinlan's condition, even if not dying, might regard all medical care with

repugnance and might consider even a minimal burden to others something to be avoided.

### I. The Case of Mr. Joseph Saikewicz

The recently decided Massachusetts case, *Superintendent of Belchertown State School v. Saikewicz*, poses a different problem. Mr. Saikewicz was an institutionalized, sixty-seven-year-old man. He was so severely retarded that he could not communicate verbally. He had been in general good health but became ill. Acute myeloblastic monocytic leukemia was diagnosed.

This disease is considered incurable, although chemotherapy is regarded as appropriate treatment for it. Such treatment is painful, often has serious side effects, and requires some cooperation from the patient. Without therapy the patient dies without great pain or discomfort. With treatment the patient often dies in a short time due to complications of the treatment itself or, despite the therapy, due to the disease. But if the therapy is successful, a remission of the disease occurs. The remission might be as short as a few weeks or as long as several years. The prognosis for successful therapy is better in younger patients.

The Belchertown State School sought appointment of a guardian to consent to treatment on behalf of Mr. Saikewicz. A probate court appointed a guardian who investigated the matter and reported to the court that he did not believe the therapy would be in Mr. Saikewicz's best interests. The probate judge accepted the guardian's recommendation but also referred the case for appellate review. Review was granted by the Supreme Judicial Court of Massachusetts, which approved the lower court's decision on July 9, 1976. Mr. Saikewicz died September 4, 1976. A full opinion had been promised and was finally issued over a year later, November 28, 1977.<sup>75</sup>

The Massachusetts high court argues that the noncompetent person has the same rights with respect to care as has the competent person. Competent persons are held to have the right to refuse treatment; this right is an aspect of the right of privacy, conceived of as "an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life."<sup>76</sup> The right to decline treatment might sometimes be overridden by a state interest in preserving life, in preventing suicide, in protecting the rights of other persons such as dependents, or in protecting the integrity of the medical profession. But the first interest does not obtain if the patient is incurable as Mr. Saikewicz was; the second and third were irrelevant; and the integrity of the medical profession was not threatened in this case, since the decision was based on medical advice.

The court also argues that a case such as Mr. Saikewicz's poses a special

and difficult problem. On the one hand, the rights of such a noncompetent person must not be set aside. Since competent persons can decline treatment, the possibility of declining treatment cannot be excluded for noncompetent persons. On the other hand, choices for noncompetent patients must be made in such a way as to protect their own best interests. In reaching a substitute judgment concerning such patients' best interests all relevant aspects of their actual condition and circumstances must be taken into account. The question which had to be answered on behalf of Mr. Saikewicz, then, was what he himself would have considered to be in his own best interests had he been able to form and express a preference. Yet in answering this question his actual condition, including his present and future incompetency, could not be ignored.

The probate judge mentions two factors weighing in favor of treatment: the fact that most people want it and that it could prolong life. He lists six factors weighing against treatment: Mr. Saikewicz's age, the probable side effects, the low chance of significant remission, the certainty of immediate suffering, the patient's inability to cooperate in the treatment, and the "quality of life possible for him even if the treatment does bring about remission."

The Massachusetts high court holds that what most people want is not relevant; what Mr. Saikewicz would want is the issue. But his life could not be considered to be of less value than the life of anyone else, "the value of life under the law having no relation to intelligence or social position." The equation of the value of Mr. Saikewicz's life with the quality of his life is firmly rejected. The probate judge's use of the expression "quality of life" is benignly interpreted: The phrase is vague and perhaps ill-chosen but must be taken to refer to the condition of Mr. Saikewicz's life as he would have experienced it with the effects of therapy, *not* to his condition of mental retardation. The decisive factor in approving the guardian's judgment to decline treatment on Mr. Saikewicz's behalf was that in his condition he would not have been able to cooperate with the treatment; it would have meant a continuing state of pain and disorientation for him.<sup>77</sup>

In our view the substance of the opinion of the Supreme Judicial Court of Massachusetts in this case is almost wholly sound. Except for its reliance upon the supposed right of privacy, which we have criticized in chapter two, section G, the court's treatment of the liberty to decline treatment supports the same position for which we argued in chapter four. The principle of equality between competent and noncompetent persons in their rights to appropriate but not excessive treatment is the same principle upon which we are proceeding in this chapter. The grounds on which the court holds that care might be refused are some of the grounds we have articulated.

Most important, the court very clearly rejects any supposition that Mr. Saikewicz's life was inferior because of his severe retardation; it wholly ex-

cludes a quality-of-life justification for the refusal of treatment for him and thus refuses to assume that a person as retarded and ill as he would be better off dead. In this respect the Massachusetts high court has fully rectified the potential damage of the probate judge's opinion and defended the same position we have been defending.

It is easy enough to imagine other cases in which it would be reasonable to project a refusal of lifesaving care by a noncompetent person whose noncompetence is caused by a condition which also would make the care especially repugnant. Many people who are on kidney dialysis find it so objectionable that they voluntarily discontinue treatment. To a great extent this repugnance is psychological.<sup>78</sup> If a paranoid person required such treatment to survive, the treatment might be experienced as a form of torture, and it might well cause such a person extraordinary anguish. In cases of this sort one could hardly doubt that it would be reasonable to conjecture that patients would refuse such care if they were able. On this assumption the imposition of care would be an injustice.

By contrast, it ought not to be assumed that everyone who is debilitated and noncompetent would desire life without care in preference to life with it. The often-repeated assertion that pneumonia is the "old man's friend" might be true with respect to an elderly person who is dying. But even a person of advanced age and in coma who is not dying ought not to be abandoned. The question still remains whether there is anything especially repugnant about the treatment such a person requires to survive. If there is not, then treatment should be given, just as it would be provided for a younger and more productive member of society.<sup>79</sup> To assume that the elderly would be better off dead is a form of discrimination based upon prejudice in favor of youth and potential productivity.

#### **J. The Proper Locus of Decision-Making Authority**

If the principles we have outlined are the correct ones on which to determine whether a noncompetent person should or should not be given medical treatment, the question remains who will make the many judgments which are involved and how the making of these judgments might be regulated in order that noncompetent persons will neither be killed by neglect nor be treated in ways they would reasonably refuse if they were able.

Present neglect statutes tend to require that those who have the care and custody of noncompetent persons seek medical treatment for them when a reasonable person in the circumstances would consider treatment necessary and there is some way to obtain it.<sup>80</sup> These statutes could be clarified and broadened, and we shall propose that this be done in the legislation we shall outline in section M. But despite their limitations such statutes together with

prevailing customary practice tend to create a situation in which there normally are two parties involved in decisions about care for noncompetent persons.

If the noncompetent individual is an infant or has a legal guardian, the parent or guardian seeks necessary medical care, must consent to it, and can change physicians if this seems desirable. Still, physicians need not accept the decisions of a parent or guardian as determinative; they can appeal to the courts in the interest of the noncompetent person. Normally physicians shape the decision of the parent or guardian by the information and advice they give, and so they have no real difficulty in acting in accord with the decision which is made.

If the noncompetent individual is not an infant and has no legal guardian, then the locus of decision-making authority is less clear. However, the physician usually will be assumed to have the right as well as the duty to administer lifesaving treatment in accord with the ordinary standard of good medical practice. In most cases the next-of-kin of the patient will be informed about prospective treatment, and consent or release of liability will be sought. The attending physician is likely to take into account the views of a noncompetent patient's family. Thus in practice the treatment of the noncompetent adult who has no guardian as well as of the infant or noncompetent who has a legal guardian is likely to depend upon consensus between the attending physician and at least one member of the patient's immediate family or the patient's guardian.

The legislation which we proposed in chapter four would, if adopted, make even clearer that the primary locus of decision-making authority resides with the physician in case the patient is an adult who has no legal guardian; at the same time our proposal would facilitate decisions by competent persons in regard to their own future medical treatment and would make such decisions binding upon any physician who agreed to treat such persons.

If the parents or family and the attending physician of a noncompetent patient who is dying agree about what ought to be done in the way of medical treatment, then we see little reason why the law should authorize anyone else to intervene except to make sure that the patient really is dying. If the consensus favors what in fact will be overtreatment, then no great injustice is likely to be done, especially if persons who are at some time competent are able to decide effectively about their own future medical care and thus forestall unwanted treatment.

If the consensus errs on the side of withholding treatment that perhaps should be given, the fact that the patient will die regardless of neglect or treatment makes legal control difficult, since the causality of death will be unclear. Also, in the case of dying patients the considerations which might provide a basis for a reasonable refusal of medical care have considerable

force, and the physician and family are probably in the best position to appraise the weight of these considerations and conjecture what the patient if competent would choose.

Again, if the parents or family and the attending physician of a noncompetent patient who is not dying reach a consensus that some treatment ought to be given, there is little likelihood that this consensus will lead to a seriously unjust imposition of treatment upon the patient. Furthermore, it would be difficult in such a case to establish an alternative approach as more reasonable and in accord with what the patient if competent would choose.

However, if a patient is not dying, then even if the parents or family and the attending physician agree that some treatment ought to be withheld, the correctness of the judgment reached by consensus is not beyond question. This is so because the parents or family and the attending physician might agree with each other that the patient would be better off dead and might be cooperating in implementing this impermissible consensus. Also, while only a remote possibility it is not impossible that an attending physician and a patient's family might conspire to kill the patient by calculated neglect, not in the supposed interest of the patient, but in the interests of the family and perhaps of the physician as well.

It follows that the consensus of the noncompetent patient's attending physician and family ought to be determinative if the patient is certainly dying or if the consensus favors treatment for a patient who is not dying. However, if their consensus favors withholding treatment from a noncompetent patient who is not dying, their judgment cannot be considered beyond question.<sup>81</sup> Furthermore, if these two primary sources of decision-making on behalf of noncompetent patients are in conflict, then some independent authority is needed to resolve the dispute.

The number of cases in which problems can arise will be reduced if laws such as we proposed in chapter four are enacted. Further, if legislatures deem persons competent to make decisions about their own care before the age of majority for other purposes, some decisions can be made by patients themselves which now must be made by others.<sup>82</sup>

Still, there will remain many cases in which a substitute judgment must be made, and the parents or family and attending physician disagree concerning what should be done, or they agree but their consensus might well be an agreement to commit homicide by neglect. What is to be done in such cases? Sometimes guidelines are suggested without any method for making or rectifying decisions.<sup>83</sup> Such guidelines are of little help.

Some suggest but others strongly oppose resting ultimate confidence in the physician.<sup>84</sup> If the issue were a merely technical one, this confidence might not be misplaced. However, since the judgment is one which goes beyond medical competence, the physician's advice, while indispensable, can be con-

sidered final neither when the parents or family of the noncompetent patient disagree nor when the justification of that very advice is called into question.

Others suggest that parents, at least, be given absolute decision-making authority in respect to their own children.<sup>85</sup> In most cases this would be very reasonable, but when the physician disagrees or when there is a possibility that the parents are abusing their authority, then there ought to be some way to protect the infant, just as there is a way to protect it against abuse and neglect of other kinds.

A committee of physicians has been proposed and sometimes used to help make decisions about giving and withholding care, but a committee has many of the disadvantages of the single physician and also diffuses responsibility, thus to make bad decisions easier.<sup>86</sup> A guardian who is not supervised also might easily make arbitrary decisions.<sup>87</sup>

It seems to us that the rights of noncompetent persons cannot be protected unless there is liberal access to the courts when the attending physician and the parents or family disagree, or when another interested party believes that the noncompetent individual is purposely being killed by the withholding of appropriate medical treatment. Only a court can guarantee due process for the noncompetent: hear all of the evidence, weigh it impartially, and apply an articulated policy to the facts.<sup>88</sup> The courts, of course, have no monopoly on fairness, but they do have a monopoly on the legal processes which ensure so far as possible that the legal rights of all persons are protected.

As in other cases, the work of the courts in this matter ought to be guided by carefully drafted legislation. If legislation is not enacted, the courts will be left to draft their own—a task for which experience indicates the courts are not particularly well suited.

In many cases decisions on acceptance or refusal of treatment will have to be made on the basis of a close examination of the details and will have to be changed from time to time as the patient's condition changes. Such judgments almost always would best be left by the courts to a guardian designated for the purpose and given both authority and general direction by the orders of the courts. The governing statute ought to make clear what sort of persons can be considered qualified to act as guardians for noncompetent patients.

In some cases it might be argued that the noncompetent patient's best guardian will be a member of the family. This view can be sound, for family members are likely to be in a good position to know what the patient would desire. However, if the interests or the attitudes of the family conflict with the interests of the patient or the standards required by public policy, then a guardian from outside the family will be a better choice. What such a guardian lacks in intimate knowledge of the relevant facts, he or she is likely to make up in objectivity in judging both the relevant facts, and the irrelevance of factors which ought not to be allowed weight.

## K. Criticism of Arkansas and New Mexico Statutes

Two of the statutes regarding the refusal of treatment passed in 1977—those of New Mexico and Arkansas—include provisions for execution of a document by one person on behalf of another.

The Arkansas statute is predicated on the assertion of a right to die with dignity and provides for the making of a document with the formalities required for a will to refuse the use of “artificial, extraordinary, extreme or radical medical or surgical means or procedures calculated to prolong” one’s life or, alternatively, one “to request that such extraordinary means be utilized to prolong life to the extent possible.” Any person may make such a document for himself or herself. The third section provides for the making of a document on behalf of a minor or an adult who is somehow incapacitated from executing such a document. It must be executed in the form of a will:

(a) By either parent of the minor; (b) By his spouse; (c) If his spouse is unwilling or unable to act, by his child aged eighteen or over; (d) If he has more than one child aged eighteen or over, by a majority of such children; (e) If he has no spouse or child aged eighteen or over, by either of his parents; (f) If he has no parent living, by his nearest living relative; or (g) If he is mentally incompetent, by his legally appointed guardian. Provided, that a form executed in compliance with this Section must contain a signed statement by two physicians that extraordinary means would have to be utilized to prolong life.

The fourth section of the act releases persons, hospitals, and other institutions from liability which might otherwise arise out of “failure to use or apply artificial, extraordinary, extreme or radical medical or surgical means or procedures calculated to prolong such person’s life.”<sup>89</sup>

This statute is an attempt to assure that there is a definite locus of decision-making authority in respect to the care of minors and noncompetent individuals. It opts for locating the authority in the family by designating in sequence various relatives who might make decisions. Probably the legislators were moved by the *Quinlan* case and wished to prevent control by physicians against the wishes of the family in a case very similar to that.

The legislation does not respond to the entire breadth of the problem, for it does nothing to remedy cases in which physicians and family agree to non-treatment in violation of the rights of a person whose life they believe to be not worth living. Moreover, the vague and unhelpful notion of “extraordinary means” is pivotal and is not defined in the statute.

In concept the law seems to assume that the patient would be in terminal condition when the document becomes effective, but this requirement is not expressed; therefore, attention is not directed to the very critical question of

whether the patient is dying or not. The legitimate bases on which one might construct either consent or refusal of treatment are not stated. The formulation by the document of what can be done seems to assume that in any case only one decision is needed and that no one could reasonably wish to accept some forms of treatment while rejecting others.

The listing of persons who can act on behalf of a minor or noncompetent is likely to create confusion and uncertainty. Either parent can act, and a conflict will arise if they act inconsistently. If a spouse is unwilling to act, this unwillingness can be overridden by an adult child or by a majority of such children. Conflicts will arise if the spouse acts to require treatment to be continued and the children order that it be stopped, and also if an even number of children favor and oppose continuation of treatment.

Apart from the case of a minor, the statute leaves unclear when a person should be considered incompetent to the extent that another can act for him or her. What will happen if a patient is too weak to make a document but is able to speak with effort?

Finally, the statute makes no provision for a hearing before a court to hear evidence on factual questions and to assure that the rights of the noncompetent individual are protected.

The New Mexico statute turns on the definition of terminal illness as "an illness that will result in death . . . regardless of the use or discontinuance of maintenance medical treatment" and the definition of maintenance medical treatment as "medical treatment designed solely to sustain the life processes." The statute specifies no form for the directive to physicians. It does prescribe that the document is to state that in case terminal illness is certified, maintenance medical treatment shall not be utilized for the prolongation of life. The certification is to be by two physicians, one the patient's attending physician, in writing; physicians certifying terminal illness are presumed to be acting in good faith, and physicians acting in accord with a declaration are released from liability.

The fourth section provides for the making of a document for the benefit of a terminally ill minor. If the minor has a spouse who has reached the age of majority, then the spouse may act; if not, a parent or guardian may act. However, if the minor who is terminally ill gives "actual notice of contrary indications" or if action by a parent or guardian is opposed by a spouse or other parent or guardian, then the document may not be executed.

The document is ineffective without the certification of a judge of the district court where the minor is domiciled or maintained. The court must appoint a guardian ad litem for the minor, and judges are to certify the document only if they are satisfied "that all requirements of the Right to Die Act have been satisfied, that the document was executed in good faith and that the certification of the terminal illness was in good faith."<sup>90</sup>

Again, this legislation does not deal with the case in which treatment which ought to be given is omitted. The pivotal concept of terminal illness is introduced but not defined as clearly as might be wished, and the hearing is directed to investigate, not the question of fact, but only the good faith of the physicians certifying it. Legitimate bases upon which one might construct consent to treatment or refusal of treatment are not stated, and this legislation also assumes that only one decision is appropriate: either to continue or altogether to withdraw "maintenance medical treatment."

The requirement that a document not be executed if there is disagreement expressed by the minor patient, by a spouse if there is one, or by either parent or guardian, together with the requirement that the patient's own physician certify terminal illness, in practice would mean that lifesaving treatment should be withheld only when there is unanimity among those most intimately involved. Since the law deals only with minors, it makes no provision for a case like that of Miss Quinlan.

Moreover, although the parent or guardian of a minor could change physicians and thus secure agreement, the situation is confused by the requirement that the minor's own expression of wishes can block action. If the minor is considered competent to determine what must be done, then it is difficult to see why the minor's wishes should be effective only in the blocking of a declaration.

The judicial hearing and appointment of a guardian ad litem respond to the need for due process. But the deficiencies in the act prevent this hearing from being fully effective, because the court is not directed to consider vital questions of fact, is not provided with standards for constructing a reasonable decision on behalf of the minor, and is not directed to appoint a guardian qualified to decide about care on legitimate bases in case the parent or guardian and physician are proceeding on the assumption that the patient ought to be allowed to die because he or she would be better off dead.

Finally, the statute does not do anything to provide for cases in which the patient is not terminally ill but consent to treatment which is necessary to preserve life might nevertheless reasonably be refused.

#### **L. The Decisions in *Quinlan* and *Saikewicz* Criticized**

The decision of the Supreme Court of New Jersey in the *Matter of Quinlan* also must be considered as an attempt to legislate a solution to the problem of the construction of reasonable decisions concerning the medical care of non-competent persons. The court conceives the problem as one which had arisen because of developments in technology making it possible to keep a person in Miss Quinlan's condition alive. The court admits that the physicians declined

to discontinue treatment in accord with "then existing medical standards and practices." The legislative intent is then explicitly stated:

Under the law as it then stood, Judge Muir was correct in declining to authorize withdrawal of the respirator.

However, in relation to the matter of the declaratory relief sought by plaintiff as representative of Karen's interests, we are required to reevaluate the applicability of the medical standards projected in the court below. The question is whether there is such internal consistency and rationality in the application of such standards as should warrant their constituting an ineluctable bar to the effectuation of substantive relief for plaintiff at the hands of the court. We have concluded not.<sup>91</sup>

The court then proceeds to argue that the standard of medical practice permits termination of active treatment in the case of dying patients.

It had already argued that Miss Quinlan had a constitutionally protected right of privacy which would permit her to refuse treatment and that this right could be exercised on her behalf by her "guardian and family."<sup>92</sup> The court suggests that the problem lay in the possible contamination of medical judgments by the self-interest or self-protection concerns of physicians and proposes to take care of this possibility by the institution of a hospital ethics committee to share responsibility.<sup>93</sup> The court's holding in the case appoints Mr. Quinlan guardian of his daughter's person, explicitly saying that he might change physicians. Then the holding is stated:

Upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefore on the part of any participant, whether guardian, physician, hospital or others.

The court then adds a footnote:

The declaratory relief we here award is not intended to imply that the principles enunciated in this case might not be applicable in divers other types of terminal medical situations such as those described by Drs. Kor-ein and Diamond, *supra*, not necessarily involving the hopeless loss of cognitive and sapient life.<sup>94</sup>

The testimony of the physicians referred to by the court merely indicated that in some cases of terminally ill patients who are not already cerebrally dead aggressive treatment might be discontinued, especially with the consent of the family, on the ground that the patient "has lost human qualities" or that treatment "does not serve either the patient, the family, or society in any meaningful way."<sup>95</sup> The court concludes its opinion with the following:

By the above ruling we do not intend to be understood as implying that a proceeding for judicial declaratory relief is necessarily required for the implementation of comparable decisions in the field of medical practice.<sup>96</sup>

In this way the court attempts to ensure that its judgment in the case will serve not simply as legal precedent for courts but as effective legislation to be followed, without further appeal to the courts, by those involved in decision-making for the noncompetent and responsible for their care.

Like the legislatures of Arkansas and New Mexico, the Supreme Court of New Jersey failed to grasp the amplitude of the problem of protecting the rights of the noncompetent in the matter of medical care decisions. The court attempts to legislate, but nothing in its decision speaks to the case of an infant left to starve in a nursery because parents do not want it and physicians agree that it would be better off dead. Indeed, the loose legislation which the court has enacted will tend, if anything, to weaken the previously existing protection of such an infant.

In chapter four, section E, we criticized the court's use of the concept of a constitutional right of privacy. One additional unfortunate implication of framing the problem in terms of such a right is obvious here: The right of privacy might protect a patient from overtreatment, but it does not call attention to the patient's right to a fair share of treatment, a share which those responsible for noncompetent persons have a duty to obtain or to provide. Since the rights to receive as well as to refuse treatment are not given equal attention, the court's decision creates a danger that the equal protection of the law of homicide will be denied to the noncompetent, who will be killed by malevolent denial of due care.

Although the court realizes that medical standards cannot be altogether determinative and that someone must decide on behalf of the patient, these two matters are not clearly related to one another. The court apparently considers medical standards to be unclear and inconsistent—which perhaps they are—and assumes the task of amending them.

A much better approach would have been to recognize that physicians have no right to treat patients except in accord with consent and that lack of such consent is a relevant circumstance for determining what good medical practice demands. We argued this point in chapter four. Had the court taken this approach, it would not have had to challenge the standards of the attending

physicians and would have focused attention upon the question of the patient's consent and the need for adequate standards for constructing a decision when the patient is unable to decide.

The court considers matters in the context of an assumption that the patient is dying. The careful definition of this condition is not investigated, nor was the question of fact fully examined. The problems which arise with respect to nondying patients are not touched.

The court refers to Miss Quinlan as comatose and unable to return to a "cognitive, sapient state"; these conditions are not precisely defined, although one might argue that the testimony at the trial by which the language was introduced into the record provides some definition. That testimony seems to indicate that something more than the consciousness characteristic of a normal infant is intended.

One physician explained "sapient" as meaning "perceptive, intelligent behavior, as opposed to vegetative responses, as opposed to vegetative expressions," while another defined "useful recovery" as a level of consciousness in which a patient "is able to function with discriminate senses, sapient sense, that is, to make judgments and to function in a humanistic sense."<sup>97</sup> This rather vague language could be construed to exclude defective infants, the severely retarded, the incurably insane, and the very senile. And the court's footnote indicates it wants its legislation also to apply to a wider range of cases of terminally ill patients.

The court lays down no qualifications for a person to be appointed as guardian with authority to make the substitute judgment. In fact, most remarkably, the court does not seem to realize that the key to the solution of the instant case is the appointment of Mr. Quinlan, who could not have put into effect his judgment on behalf of his daughter without the court's action. So there is no indication how other cases, which the court wishes to have settled without adjudication, will resolve the issue of guardianship.

At the same time the court mandates consultation with a hospital committee. This diffuses responsibility and infringes upon the rights of the patient, for if the proper position is that the guardian can act for the patient, then refusal of treatment on the patient's behalf ought to have removed authority for the hospital and physicians to continue that treatment, just as refusal by a competent patient ought to require a physician to desist from unwanted treatment. In other words, the court to some extent imposed continued treatment upon Miss Quinlan by setting requirements for the termination of treatment which undermine the principle that a person should not be treated without consent.

It is interesting to notice, moreover, that New Jersey hospitals did not have committees such as the court prescribed and subsequently set them up in response to the new legislation by the court.<sup>98</sup> The idea of an ethics committee

to share responsibility had been suggested in a law review article, with qualifications which the New Jersey Supreme Court deleted.<sup>99</sup> We consider this idea objectionable. Ethics committees would add fresh complications, diffuse authority, and dilute the patient's rights without guaranteeing due process and equal protection to those patients who are being killed by omission.<sup>100</sup>

The Supreme Court of New Jersey is unduly concerned to keep cases out of the courts. The court holds that problems of the sort involved here can be distinguished from the commitment of noncompetents and other matters which must be processed through the courts.<sup>101</sup> Undoubtedly there are differences, but the court does not say what they are. Moreover, if a person's liberty cannot be limited without legal process, it is hard to see why life should be limited when there is a question about the legitimacy of so doing without a process.

The Court is no doubt worried about the limits of judicial competence in medical matters, but this worry is misplaced. The problem with noncompetent patients as with competent ones is not a need to review technical decisions within the expertise of the physician, although in some cases expert testimony might be needed to settle matters of fact, such as whether a patient is dying or not, and whether a proposed treatment is likely to have certain effects. Rather, the problem with noncompetent patients is to construct a reasonable decision on their behalf, in order that they receive the care which they deserve and would want and that they do not receive treatment they would not want.

Courts can and must determine that persons are not competent to decide for themselves when they are not, find whether the patient's condition would or would not support a presumption for or against treatment, and select a guardian and provide the guardian with guidance about the legal policy which must be borne in mind in deciding on the patient's behalf. No procedure which does not involve a judicial hearing can adequately protect the rights of patients in these matters when the ordinary decision-making process breaks down or seems to someone concerned to be yielding unjust decisions with respect to a particular patient.

Finally, the Supreme Court of New Jersey wants what it calls the principles it enunciates in *Matter of Quinlan* to be applied in other more or less similar cases without a judicial hearing. But what were these "principles?" Is the intention that treatment might be terminated whenever a patient is terminally ill and the family wishes treatment terminated? Does the court desire that a parent of an adult be accepted by others as a legal guardian without recourse to the courts? Does the court intend to exclude criminal and civil liability in all cases where treatment is terminated? No one knows.

In contrast to the effort of the Supreme Court of New Jersey in its decision in *Quinlan*, the Supreme Judicial Court of Massachusetts in *Saikewicz* affirms

the responsibilities of the courts in deciding issues concerning medical care for noncompetent persons. The Massachusetts high court states that the case was properly brought to probate court, where the rights of Mr. Saikewicz could be protected. For the future the court calls attention to statutory requirements which ought to be followed. It directs that in a hearing on a petition for the appointment of a guardian for an alleged noncompetent person, the person also be represented by a guardian ad litem, an advocate who will press whatever case there might be for treatment.

The decision whether to give or withhold treatment regarding a person found noncompetent is reserved to the probate judge. This decision is to be made on the standards clarified in the instant case. The judge may seek expert advice as needed. If a hospital has an ethics committee or other consultative body, the judge will listen to its advice. But the authority to make decisions is not to be abdicated to any such body, and the directive in *Quinlan* to this effect is explicitly rejected. Questions of life and death deserve and require the due process for which the judicial branch of government was created. The responsibility is not to be shunted off to some other group representing the social conscience.<sup>102</sup>

The Massachusetts high court's treatment of the issues and procedural guidelines is much superior to that of the Supreme Court of New Jersey. Yet the Massachusetts opinion also raises certain difficulties. Does the decision mean that every single medical judgment with respect to a noncompetent person must be contingent upon the outcome of a judicial procedure? The court does not clearly exclude this interpretation, although it does state in a note that it does not intend to lay down general guidelines concerning emergency medical care for the noncompetent but leaves this task to the legislature.<sup>103</sup>

William J. Curran and Arnold S. Relman, in separate, brief articles in the *New England Journal of Medicine*, attack the requirements for a judicial hearing laid down in the *Saikewicz* decision by claiming that the court is invading the proper province of medical judgment, requiring unnecessary and time-consuming litigation, and showing an undue lack of confidence in the existing medical-care system. The nub of the critics' dissatisfaction with the decision, however, is most clearly revealed in Curran's observation:

The Court seemed to want to make it clear that a mentally retarded person's life was fully worth saving. This ruling could mean that brain damage to an infant or very serious burns and disfigurement and limited bodily functioning could not be taken into consideration in offering or withholding resuscitation or intensive care to a patient. This interpretation could present very serious implications for medical decision making.<sup>104</sup>

Similarly, Relman cites the articles by Shaw and by Duff and Campbell published in 1973 in the same journal—articles which exposed and defended the

practice of selecting infants for nontreatment on quality-of-life criteria. Relman claims these articles showed the complexity of the problem, but he says that few until the *Saikewicz* decision suggested that the physicians and next of kin could not be trusted to make these difficult decisions.<sup>105</sup>

George J. Annas, by contrast, in another journal comments favorably to the decision in *Saikewicz*. According to Annas the questions to which the Massachusetts high court directs attention are the correct questions. Moreover, while a legal procedure is difficult, it is the only way to guarantee both the noncompetent person's rights not to be treated excessively and not to be purposely killed by neglect.<sup>106</sup>

We believe Annas is correct, although the *Saikewicz* decision certainly leaves unclear the extent to which cases must be brought to court. Moreover, the criteria for decision are not spelled out as clearly and fully as they should be. Presumptions are not established in cases in which patients are not dying. And the qualifications of persons to be appointed as guardians are not considered. The court perhaps hopes that the legislature will address itself to all of these problems. If so, we think that the *Saikewicz* decision points precisely toward the proposal we now make.

#### M. Outline of an Adequate Statute

The previous discussion has shown that legislation is needed to protect the rights of noncompetent persons in receiving their fair share of medical care and in not having excessive care imposed upon them. We have proposed legislation in chapter four to take care of the right of competent persons to refuse treatment. Here we assume that this proposed legislation is enacted, and thus the number of noncompetent persons for whom choices must be constructed is somewhat reduced.

Also, in the legislation we outlined in chapter four the provision is clear that physicians have primary decision-making authority in respect to noncompetent persons who are not minors and who have no legal guardian. Unless directed otherwise by a court, a physician is to assume that the noncompetent person under care consents to appropriate treatment to remedy an existing condition of disease or injury. To some extent the legislation we are now going to propose will call into question the appropriateness of the treatment which a physician acting in good faith might give; consent might be construed to limit treatment which the ordinary standard of medical practice would otherwise require.

The legislative findings, on which the legislation we are about to propose might be grounded, could be along the following lines.

The basic principle is that every person has a right to a fair share of

available medical treatment, especially if such treatment is required to preserve life. No one can justly be deprived of medical care on the ground that he or she has in prospect a life which some might consider to be of poor quality.

It follows that those having care and custody of noncompetent persons must obtain or provide for them so far as possible appropriate medical care for any existing condition of disease or injury when a reasonable person in the circumstances would consider such care necessary. Although economic limitations require that costly medical treatments be optional in certain circumstances, the costs of treatment cannot justly be accepted as a basis for limiting treatment of those considered by some to have in prospect a life of poor quality if treatment otherwise would be obtained and provided.

It also follows that an injustice is done to noncompetent persons if medical treatment is imposed upon them in circumstances in which any reasonable and competent person would refuse treatment. Many reasons might be considered by a competent person sufficient to refuse medical treatment, and quite apart from any intention of hastening death a person might prefer a briefer life without treatment to a longer life with it. In unusual cases even treatment needed to preserve life might be refused without suicidal intent by a competent person who is not dying. The possibility that noncompetent persons might wish to refuse treatment if they were able to do so must be recognized, and the right of noncompetent persons to avoid excessive treatment as well as to obtain appropriate treatment must be protected.

Another point which the legislative findings should mention is that persons who are dying are far more likely than those who are not dying to have reasons for refusing medical treatment, since the disadvantages of accepting treatment appear greater as its probability of preserving life and restoring health appears less. The question whether a person is dying is a matter of fact to be determined by evidence.

Furthermore, a method of deciding on behalf of the noncompetent patient whether medical treatment is to be accepted or refused is needed to protect the right of such a person to appropriate but not excessive treatment. The right to be protected neither presupposes nor implies any right to die. Nor is this right properly considered an aspect of the right of personal privacy, which pertains to liberty. Noncompetent persons cannot exercise their liberty, and no one can exercise a person's liberty on his or her behalf.

The problem to be dealt with by the legislation is that while in most cases the rights of noncompetent persons are at present sufficiently protected, in some cases these rights are not adequately safeguarded. Some people have made their wishes known during a prior period of competence. Many are suitably treated in accord with a judgment shaped by an attending physician and concurred in by family members or others closely concerned with the

well-being of the noncompetent patient. But in some cases those who bear such responsibilities to the patient are unable to reach consensus, and in a few cases they reach a consensus which violates the rights of the person for whom they are responsible.

It is important for the legislature to point out that in some cases persons who would not have died with appropriate and available medical treatment have been deprived of such treatment for the benefit of society or their families, or on the theory that they would be better off dead. In such cases the crime of homicide is committed by omission, which is no less criminal than homicide by deed. Homicide by omission cannot be justified by asserting that the person killed in this way would have agreed to it, for such an agreement would have been suicidal in intent and would have been consent to homicide. Neither assisted suicide nor homicide with consent is lawful, and suicide is contrary to public policy.

Certain duties which already exist, but which are to be reinforced by the statute, should be summarized. Every person who has knowledge such that a reasonable person would suspect that homicide is being committed, whether by omission or by deed, has a duty to inform the police in order that life may be protected and the law enforced. Police and prosecutors have as grave a duty to prevent and punish crimes by omission as those by deed. Every person who believes that a noncompetent person is suffering grave mistreatment or neglect has a duty to call the matter to the attention of the public welfare authorities. These authorities have the duty to protect the welfare of noncompetent persons who otherwise would be deprived of the necessities of life.

The crux of the problem is that noncompetent persons including those whose quality of life is considered poor by others have the same right as any other person to due process of law and equal protection of the laws. Thus if there is doubt as to what decision concerning medical care ought to be attributed to any noncompetent person, this doubt should be resolved in accord with the provisions of law by a judicial hearing. Since the graver injustice will be done to a noncompetent person if life-preserving care is withheld which ought to be given, the initial presumption in any such case is that such treatment required to preserve life would be accepted. However, this presumption can be rebutted by evidence, especially in the case of a person who is dying, but even in certain cases of a person who is not dying.

A declaration of legislative findings along the preceding lines would summarize the conclusions for which we have argued in previous sections. Some might object to the requirement that anyone who knows of a suspected case of neglect or homicide by omission must report it. But this duty is implicit in existing law. Moreover, statutory requirements that physicians report child abuse are not uncommon.<sup>107</sup> The onerousness of the reporting requirement

can be lessened for the person reporting if confidentiality is maintained. The results of reporting can be lessened for others involved if police and public health authorities undertaking any investigation of a report realize that what appears to someone to be homicide by omission or grave neglect might nevertheless be a reasonable effort to avoid excessive treatment.

The statute will require a number of important definitions, which must be supplied in accord with the existing law of each state. For example, "medical treatment" might be defined as treatment provided by certain classes of persons and institutions acting professionally and lawfully, to exclude forms of care and treatment which nonprofessional persons normally can provide to themselves or others in their care without prescription or special training and direction by a professional person. "Ordinary nursing care" might be defined as those forms of care which a person who is sufficiently alert and strong could and would provide for himself or herself, or which a mother could and would provide for her infant.

"Responsible persons" can be defined to include all who share in the responsibility of obtaining or providing medical care for noncompetent persons, including but not limited to attending physicians or nurses, administrators of hospitals or other institutions of which noncompetent persons are inmates, parents or guardians of infants and wards, family members sharing a common domicile with the noncompetent, and the spouses and offspring of noncompetent adults.

"Primarily responsible persons" would have to be defined with great care, for this expression would designate those whose judgments in many cases will be determinative. One of the primarily responsible persons will be the attending physician of a patient, or the physician primarily in charge of the medical care of a patient. In jurisdictions in which it is possible at present that a patient be under medical care without a particular physician being identified as the attending physician, provisions will be needed to prevent this situation.

The other primarily responsible persons, if any, will be determined by the status of the patient. Parents normally are primarily responsible for infants; either parent might be authorized to act if only one is present, but if both are present and not in agreement, then neither can act. For legal wards the legal guardian is primarily responsible. For noncompetent adults domiciled with their immediate families or relatives, some jurisdictions have definitions of "next of kin" which might be adopted or modified. A person domiciled with a spouse would have the spouse as primarily responsible; a person without a spouse domiciled with an adult child would have the child as primarily responsible—or the elder or eldest of two or more such children. For persons normally residing in institutions wholly responsible for their care and custody the chief administrator of such institution would be primarily responsible.

The most important definition in the statute will be that of "dying." A

person is dying only if there exists in him or her a condition of disease or injury such that beyond reasonable doubt the condition will be at least an underlying cause of death, provided that no one is considered dying if available medical treatment can prevent death due to an otherwise fatal condition and that no one is dying who in the opinion of medical experts concerning the condition will not succumb to it regardless of treatment within one year. The last provision would exclude from the status of dying those persons who have contracted a disease known to be eventually fatal but which can be held at bay for a prolonged time by suitable treatment. Some such limitation seems to us necessary for legal purposes, although not essential to the idea of "dying person."

The statute will require a clear determination of those persons to whom it applies. We believe that with respect to minors the best solution is to draw a clear line by designating an age under which parents will be recognized as primarily responsible and authorized by law to make judgments which normally shall be binding upon physicians, just as when competent patients make a judgment in respect to their own care. The age to be set is a matter of dispute, and we leave it open here as we did in chapter four. The one essential point is that the age of competence to make medical decisions must be uniform both for the statute outlined in chapter four and for the one proposed here.

Apart from cases in which the noncompetent person is a minor or a legal ward of a guardian, the determination of competency is an instance of a general problem from which we prescind throughout this book.

Physicians will have decision-making authority according to the provisions of the law we outlined in chapter four, but they normally will act or refrain from acting only with the consensus of others primarily responsible for the patient. In case of disagreements the issues will have to be settled by a judicial proceeding, and the first issue in such a proceeding will be the question of competency of the patient if this question is disputed by anyone concerned.

Most jurisdictions already have statutes requiring parents to provide the necessities of life for their children and characterizing as neglect failure to do so. The statute proposed here might well begin its regulative provisions by broadening this obligation to include whomever shares responsibility for a noncompetent person in respect to the obtaining of medical care which a reasonable person would consider needed. But except for those primarily responsible, others could discharge their responsibility by calling to the attention of the public welfare authorities any case of apparent neglect.

Although certainly implicit in existing law, the statute ought also for the sake of clarity to require that anyone who suspects homicide by omission should inform the police of any facts upon which the suspicion is based. The

police should be enjoined to investigate such reports with the same vigor as they would any other report of a homicide in progress. The welfare authorities and the police should be required to communicate information to one another, so that both will be able to act in fulfillment of their respective duties, regardless of which first receives relevant information.

In cases in which a parent or legal guardian refuses medical care for an infant or ward physicians should be held, not to seek a court order authorizing treatment, but to report the matter to the public welfare authorities. If there is any indication that the care refused would be appropriate, the welfare authorities should be required to seek the judicial hearing. The same will be the case if those primarily responsible agree in withholding care which might be appropriate. In cases in which the evidence is that excessive treatment is being administered to a noncompetent person those considering the treatment excessive would have responsibility for seeking a judicial hearing.

The heart of the statute would be the prescription of the issues to be considered by the court, the standards to be applied in adjudicating the issues, the presumptions which are to be considered in possession, the qualifications for a person to be appointed guardian, and the authorization of the guardian to act on behalf of the noncompetent person.

The court's first duty should be to determine whether the patient was in fact an infant, a legal ward, or an otherwise noncompetent person. The next issue would be whether the noncompetent person is dying or not according to the statutory definition of "dying." If necessary, expert examination and testimony would be sought to settle this issue. It should not be considered resolved by the stipulation of all parties that the patient is dying, but it could be resolved by their stipulation that the patient is not dying. The next issue would be whether the noncompetent patient should be presumed to have reasons for refusing available medical care, although the care could be considered by at least some physicians appropriate in the existing circumstances.

The court should proceed on the following presumptions. If a noncompetent patient is dying, then agreement between those primarily responsible for the patient concerning what care is proper should be presumed conclusively to express the choice of the patient. If the patient is not dying, then agreement between those primarily responsible for the patient that care or treatment be given to prolong life or preserve or restore health should again be presumed conclusively to express the choice of the patient. If a noncompetent patient is dying and those primarily responsible for the patient disagree concerning what care is proper, then the court should consider in possession the presumption that the patient's next of kin expresses the patient's wishes, but this presumption will be subject to falsification by the preponderance of the evidence. If a noncompetent patient is not dying and those primarily responsible for the patient disagree about whether care or treatment be given

to prolong life or preserve or restore health, then the court should consider in possession the presumption that the patient would desire medical care. If a noncompetent patient is not dying and those primarily responsible for the patient agree that care should not be given, then the court must find whether the patient's life is likely to be shortened by omission of care; if so, the presumption in possession should be that the patient would desire care; but if not, the presumption in possession should be that the patient would refuse care.

Where conclusive presumptions are established, a case could be terminated with an order which would have the effect of legally establishing the patient's own decision concerning treatment, thus to free all concerned from the civil or criminal liability which they might otherwise fear if medical treatment were given or withheld in a state of uncertainty as to the patient's consent to or refusal to consent to treatment.

Where rebuttable assumptions are established, the court should hear evidence relevant to determining the probable advantages and disadvantages of available medical treatment for the patient. In the case of dying patients such evidence would be that treatment could prolong or enhance the patient's ability to act and to have experiences desirable to him or her, in comparison with evidence that treatment would be considered undesirable.

The grounds for considering treatment undesirable, articulated in section E, ought to be specified in some detail in the statute: the treatment is experimental or risky, it would be painful or otherwise experienced negatively, it would interfere with activities or experiences the patient might otherwise enjoy, it would conflict with some principle to which the patient adheres, it would be psychologically repugnant to the patient, or the patient would consider the financial or other impact of the treatment upon other persons a strong or even morally compelling reason for rejecting the treatment.

If a noncompetent patient is not dying, then the probability that available treatment might prolong life or preserve and restore health also ought to be considered to the extent that it can be determined by evidence in favor of prolonging treatment.

In hearing the evidence the court should be directed by statute to exclude carefully evidence concerning the patient's prospective quality of life except insofar as such evidence bears upon the patient's own probable lawful wishes concerning treatment. In other words, the court should be careful to rule out of order arguments claiming that survival would be undesirable due to the patient's condition of debility, age, declining strength, mental or physical handicap, or other disadvantage.

Where the court judges that the evidence presented preponderantly supports the presumption in possession, the case could be terminated. If the issue arose because of disagreement among those primarily responsible for

the patient, then one of those whose initial position agrees with the decision which the court finds should be attributed to the noncompetent patient may be appointed guardian unless upon examination this person is found unqualified. If the issue arose because those primarily responsible agreed with one another contrary to the presumption soundly to be in possession, then another qualified person should be appointed guardian. In any case the guardian should be charged to make decisions in accord with the finding.

Where the court judges that the evidence presented does not preponderantly support the presumption in possession, a qualified guardian should be appointed and charged to make decisions in the light of the evidence and other information which the guardian obtains from time to time.

The decisions made by a court-appointed guardian, provided that they are made in good faith, should be final, just as a competent person's decisions with respect to his or her own care should be considered final. Moreover, such decisions should be considered a relevant circumstance in determining the standard of due medical care, so that physicians and hospital authorities will not be held liable for limiting or modifying care in accord with such decisions.

The qualifications for appointment as a guardian should include the following.

First, no one should be appointed guardian who does not agree with the public policy that assisted suicide and homicide with consent are acts rightly held to be criminal, that homicide by omission is as grave a crime as homicide by deed, that every person is entitled to a fair share of available medical care regardless of such person's prospective quality of life, that the refusal of life-prolonging medical treatment sometimes is reasonable and lawful, and that a person's own choice if he or she were able to make it should determine the limits of treatment to be given provided that such choice is not suicidal.

Second, no one should be appointed guardian who has a personal interest potentially averse to that of the patient in the results of decisions he or she is likely to be called upon to make.

Third, no one should be appointed guardian who lacks the knowledge and intelligence necessary to understand the condition of the patient, the possible benefits and disadvantages of treatment, and the legal policy which requires that decisions be made from the patient's viewpoint and in disregard of factors held by law to be irrelevant.

In terminating cases and appointing guardians the court should explicitly direct that if certain medical treatment is lawfully withheld from a noncompetent patient, there nevertheless remains an obligation to provide care and treatment suited to the patient's condition, including ordinary nursing care and such palliative care as may mitigate the patient's suffering.

In some jurisdictions it would be desirable to clarify the possibility and

limits of a parent's being relieved of rights and responsibilities for a child. In cases in which lifesaving treatment is ordered for an infant unwanted by the parents removal of the infant from their care might be indicated. If so, the statute also should settle the question of financial responsibility. It seems reasonable that parents who are able should contribute at least to the extent of the normal cost of raising a child if they are to be relieved by the state of this responsibility.

Consideration ought to be given to the possibility of establishing a public office concerned with the medical care of the noncompetent. Such an office might be assigned the duties we have proposed be given to the public welfare authorities, including the receiving of information and the filing of cases on behalf of the noncompetent. The office also might have on its staff persons qualified to act as guardians; such individuals by increasing experience might be more able than others to assume the tasks of guardian when appointed to the role.

In addition, a public office concerned with the medical care of the noncompetent could perform quasi-judicial functions by carrying out preliminary investigations of complaints and attempting to bring about agreement in cases in which the difficulty is caused by misunderstanding or ignorance of the legal requirements. A well-designed procedure for resolving problems according to well-known principles with easily predictable results frequently would lead to a resolution without a court hearing of cases which could be resolved without testing presumptions in possession.

The statute ought to make clear that the liability of all concerned is limited by the legally established substitute consent of the patient but is not removed when the circumstance of the patient's consent to or refusal of treatment is taken into account.

Penalties for failing to report information on the basis of which a reasonable person would suspect that appropriate medical care is being withheld or inappropriate care imposed should be substantial but not so great as to deter their imposition. In one case—that of failure to report omissions which any reasonable person would consider homicidal—the one failing to report should be treated as an accessory or conspirator. Similarly, perjury in a hearing which resulted in the withholding of care necessary to preserve the life of a person and caused the subsequent death of that person should be treated as homicide.

The statute when enacted should be called to the attention of physicians and hospital administrators, as well as studied by relevant public employees. The legislature might well provide for special promulgation by having an appropriate state official prepare and distribute a summary of the legislation and commentary upon it to assure that all concerned, including the courts, would be prepared to implement the legislation as quickly and effectively as possible.